

The title 'Research Matters' is prominently displayed in the center-left of the page. It is written in a large, white, bold, sans-serif font. The background behind the text is a semi-transparent green circle containing various medical and scientific icons, including a human skeleton, a brain, a heart, a stethoscope, and a hand holding a tablet.

NEWSLETTER SPRING 2019

noclor

RESEARCH SUPPORT

EDITION 14

SPRING 2019

Contents

- 02 FIRST THOUGHTS**
Lynis Lewis, Noclor Service Director
- 03 PLAYING THE LONG GAME**
Boost for research in NHS 10-year plan
- 04 PROFILE: NICK LEMOINE**
Influence of CRN spreads far and wide
- 07 SHARED AMBITION**
Patients given frontline role in studies
- 08 UNTANGLING THE WEB**
Judith Stephenson on pregnancy choices
- 11 ATTRACTIVE OPTIONS**
“Smear” campaign given a positive spin
- 12 Q&A: BREXIT ANXIETIES**
Martin McKee’s fears over leaving the EU
- 14 POWER OF PARTICIPATION**
Service users’ pride of place in research
- 15 TRAINING OPPORTUNITIES**
- 16 PROJECTS RECRUITING**

First thoughts...

In the not-so-distant past, healthcare research mostly tended to involve large, academic-led studies, but times are definitely changing – as highlighted by a recurring theme of patient participation that runs through this issue of the Noclor newsletter.

It's very encouraging that the **NHS Long-Term Plan** (Page 3) aims to increase the number of people registering to participate in health research to one million by 2023/24.

Judith Stephenson (Page 8), Margaret Pyke

“A recurring theme of patient participation runs through this issue of the newsletter”

– **Lynis Lewis**,
Service Director, Noclor
Research Support



Professor of Sexual and Reproductive Health at UCL, explains how women have helped in research to develop an interactive website on contraception that advises on how best to plan and prepare for pregnancy.

A pilot study led by **Dr Anita Lim** (Page 11), of the King's College London Cancer Prevention Group, is introducing an easier self-sampling option to help reverse falling rates of cervical screening among women aged 50-64.

Professors David Wheeler and Margaret Johnson (Page 7), the new clinical directors of North Thames Clinical Research Network, have a shared ambition of giving more patients the opportunity to participate in clinical studies.

And at East London NHS Foundation Trust, the **PRIDE trial** (Page 14) has enabled mental health service users to carry out research into the benefits of People Participation (PP) teams – while improving their own health and well-being at the same time.

Our profile of **Professor Nick Lemoine** (Page 4), head of the medical directorate of the NIHR Clinical Research Network, shows how research

is spreading further and wider into the “Cinderella” areas of healthcare.

And finally, Brexit is a subject impossible to ignore at the moment. **Professor Martin McKee** (Page 12), professor of European public health at the London School of Hygiene and Tropical Medicine, adviser to the EC on health and a member of Scientists for EU, shares his fears about the damaging impact that leaving the EU will have on NHS research.



• Visit our website <http://www.noclor.nhs.uk> or follow us on **Twitter @NoclorResearch** for more news and details of how we support the vital research work carried out by our partner trusts. We welcome your feedback, as well as any suggestions for topics to be included in future issues of the newsletter.

Research wins critical acclaim in NHS 10-year plan

The critical importance of research and innovation in driving medical advances has been recognised in the NHS Long-Term Plan, with a commitment to enhancing the benefits these bring both to patients and the UK economy.

Under the 10-year plan, announced in January this year, research investment is set to double for the period 2015 to 2020, with £300 million of government support.

Patients benefit enormously from research and innovation, with breakthroughs enabling prevention of ill-health, earlier diagnosis, more effective treatments, better outcomes, and faster recovery. Research and innovation are also important for the UK economy, bringing jobs and services.

Along with measures to prevent 150,000 heart attacks, strokes and dementia cases, the aim is to increase the number of people registering to participate in health research to one million by 2023/24. People will be able to view opportunities to participate and register interest on the NHS App by 2020.

Teresa Allen, chief executive of the Health

Research Authority, said: “It is encouraging to see the plan aligns with our ongoing areas of focus, such as linking and correlating genomics and clinical and patient data.

“The UK has a worldwide reputation for the quality of the research conducted here. The HRA has an important role to play in protecting and advancing that reputation, ensuring that regulation governing research in the UK is appreciated and understood, and works for all our stakeholders.”



Growing concerns about the mental health of young people have resulted in the plan's target of increasing participation of teenagers and young adults in clinical trials to 50% by 2025, with £2.3 billion allocated to improve access to talking therapies for 350,000 children and young people, as well as 380,000 adults.

Sarah Hughes, the Centre for Mental Health chief executive, who is also undertaking a doctorate with the Tavistock and Portman Centre in London, welcomed the plan's commitment.

“For too many young people, mental health support is offered too late, with too many restrictions, and then they are forced to start again when they reach 18,” she said.

Sarb Bajwa, chief executive of the British Psychological Society, also welcomed the aim of bringing about parity between physical and mental health services, but warned that there is still a long way to go.

He said: “It is unacceptable that tens of thousands of children who need care cannot access it due to chronic staff shortages and inadequate workforce planning.”

Making research everybody's business

'Cinderella' research focus blossoms far and wide

PROFILE: Professor Nick Lemoine, head of the medical directorate of the NIHR Clinical Research Network, on the challenge of spreading out to areas of healthcare that have historically been neglected

In the previous incarnations of the Clinical Research Network, there was always strong topic-specific focus, typically in the acute hospital sector. There was a cancer network, a diabetes network, and a medicines for children network – and then there was the comprehensive research network that covered everything else.

Now we are starting to see research blossoming in areas that have historically

been a bit “Cinderella”, such as public health. Five years ago, there were just two such studies on the portfolio, but now there are 40 to 50 at any one time.

High-level objectives are being routinely met for the network and, over time, we’ve seen a broadening in terms of where research is conducted.

Today, around a third of general practices are involved in research, and we’ve also seen a growth in health service research – that is, looking at what research can do for the NHS as well for patients.

I’ve been head of the medical directorate at the NIHR’s clinical research network (CRN) – which is a half-time role – since 2014. Before then, I was a clinical director for the local network that covered central and east London, of which Noclor was a part.

Having exposure to a broad range of specialities beyond my own – which

is cancer – was interesting as I got to see the challenges and the potential overlap: how we could work with the same population for research in a number of different disciplines.

We organised the medical directorate by grouping specialities in clusters: diseases with obvious links, such as diabetes, cardiovascular disease and stroke; reproduction and maternal health with children’s health; and clusters that involve specialities with less obvious links, such as mental health, public health and health services research. Moulding the groupings was one of the attractions of the job.

Although many of our specialty leads in the medical directorate are doctors, we recognise that this might not be the optimum situation. Really, we ought to be called the clinical directorate, because we’re reaching out to a broader potential base of investigators.

Historically, our business was in trials of new drugs and medicines, but the widening of our portfolio to new areas means that we

need specialist intelligence and support from a range of clinical investigators. One of our specialty cluster leads is a professor in physiotherapy, for instance, and I would like to get away from the directorate being perceived as an exclusive club for doctors.

The emerging technologies and innovations coming over the horizon are going to change the nature of the research we do, who we do it with, and who it needs to be done by. So we’ve been looking at the impact and implications of this for the network.

An example is stratified, or precision, medicine. In 2014, the average size of a cohort for a typical clinical trial was 160 patients; now it is fewer than 100, because we’re selecting on the basis of particular characteristics.

That means we have to be slicker about how we assess the feasibility of a study in the NHS, such as how we select sites and how we train our workforce. It’s an important insight into research in the future.

We’ve also been looking at advanced imaging, what kind of imaging gets included in research studies, and the infrastructure



base needed to do the kind of scans or other types of imaging that are required for research in the UK.

It’s a changing landscape because of the increase in the number of private providers and manufacturers involved. We need to make sure we’ve got the right workforce with the right skills to do this sort of work.

Another area we’re working on is

interpreting innovations in clinical trials for hard-to-reach or historically under-represented groups.

Anecdotally, we know that older patients have less access to clinical research than younger ones. And there are geographical differences in research into particular diseases, such as lung cancer. Although 75% of the burden of chronic lung cancer is in the north of England, 75% of the research on it is done in the south.

We want to balance that inequity through the investigator community, and across the wider NIHR, by making researchers think more imaginatively about where they conduct their research to best effect.

The funding for the network has essentially been flat cash for the last eight years. With inflation, this means we’ve actually had a net decrease in the amount of resources available.

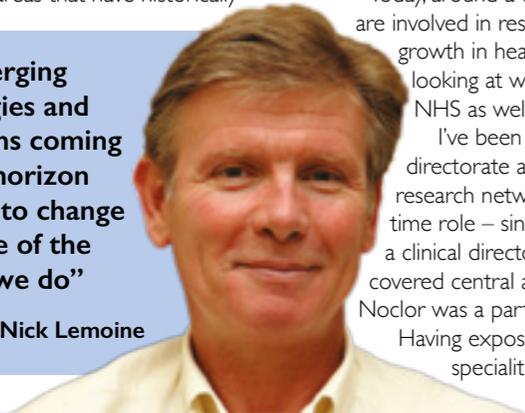
Recruitment has gone up, but we’ve now reached the absolute limit of value-for-money savings. To maintain current performance on a shrinking revenue base is going to be a big challenge.

Continued on next page >>

Making research everybody’s business

“The emerging technologies and innovations coming over the horizon are going to change the nature of the research we do”

– Professor Nick Lemoine



>> **Continued from previous page**

Also, now that the Department of Health has become the Department of Health and Social Care, we're expected to conduct research in social care environments.

That is a challenge because local authorities don't really have an investigator community, and yet there are important questions to be asked for the benefit of the UK and its population.

However, if we are having to stretch our current resource outside the NHS into other settings, there's inevitably going to be tension about how that's achieved.

The other challenging issue is multiple morbidities, or co-occurring diseases. We need to ask research questions about issues that will cross historical speciality boundaries, and the clustering of some of our specialities was designed to help lay the groundwork for that.

It's a work in progress and I think the healthcare environment in the future will shift to reflect that. Healthcare provision for individuals will need to be more organic, with multiple specialisms working simultaneously, and we'll need to do research in that environment.

Brexit is a great risk for the stability of medical research. Already some European consortia have decided not to go ahead with UK partners – for instance, on rare diseases – and this is a very worrying trend.

Any interruptions in the medicine supply chain will also affect our ability to deliver clinical studies. Medical and clinical research in the UK is going to be in for a bumpy ride, for a while at least.

Alongside my work at NIHR, I'm also



Professor Lemoine on a visit to China, where he will help to create a network of medical sciences academies for conducting clinical research.

director of the Barts Cancer Institute at Queen Mary University of London and director of R&D for cancer and surgery for Barts Health.

For the last 13 years, I've also had a personal research programme in China, looking at the development of biotherapies for cancer.

There is no primary care in China, so research is only possible in the hospital sector, whereas the majority of our patients in the CRN are recruited in primary care.

Over the last few years, I've been given the opportunity to develop an academy of medical sciences approach across China's Henan province, which has a population of 108 million people.

We will be creating a network of academies across China, and the aim is to join them up and create a framework with international standards of ethics and governance for conducting clinical research.

It's a fantastic opportunity to carry out research at scale and at pace, and to potentially look at rare diseases in a way that may be difficult, if not impossible, to do in smaller health economies. It's a fascinating challenge.

Shared ambition puts patients in forefront of studies

Giving more patients the opportunity to participate in clinical studies means taking the studies to the patients – and that is exactly what the new clinical directors of North Thames Clinical Research Network (CRN) are aiming to do.

Professors David Wheeler and Margaret Johnson took up their positions last November as a job share, having previously worked together at the Royal Free NHS Foundation Trust for 15 years. The National Institute of Health Research has extended CRN contracts until 2022.

As NIHR national specialty leader for renal disorders, Wheeler brings a UK-wide perspective to the role. He also has experience leading delivery of academic and commercial studies at an international level.

He says: "It's a new challenge for Margaret and myself, but we went in with our eyes open as we've both been divisional leads within North Thames CRN.

"We've got a great group of specialty leads in the area supporting us in the delivery of clinical studies, but we need to increase the number of patients we recruit and deliver studies on time,

Professor David Wheeler's

current positions include professor of kidney medicine at University College London, honorary consultant nephrologist at the Royal Free London NHS Foundation Trust, and honorary professorial fellow of the George Institute for Global Health, Sydney, Australia. He is a clinician scientist with an interest in the complications of chronic kidney disease.



Professor Margaret Johnson

is one of the UK's leading consultants in thoracic medicine, practising at the Royal Free London NHS Foundation Trust. She has been working as a consultant in HIV/Aids and thoracic (respiratory) medicine for more than 20 years, and has been the clinical director of medicine and medical director at the Royal Free Hospital NHS Trust. Professor Johnson has been awarded a personal chair at UCL.



despite the financial pressures that will constrain our budgets. We must strive to be more efficient."

Johnson, one of the UK's leading consultant physicians in HIV and thoracic medicine, practising at the Royal Free Hospital NHS Trust, was, until recently, academic vice-president of the Royal College of Physicians. She says: "My biggest impact at RCP was raising issues around research for all.

"The North Thames role is giving me a real

opportunity to put into practice what was major policy output from the RCP, by making sure that many more clinicians and patients right across the network are able to get involved in research."

Traditionally, the focus has been on large, complicated trials run from the big teaching hospitals, but many of the newer trials are for patients who are managed by their GPs and may not visit the hospital clinics.

The CRN is starting to recruit from other settings, including schools and nursing homes.

Making research everybody's business

Choices untangle contraception's web of confusion

Judith Stephenson, Margaret Pyke professor of sexual and reproductive health at UCL, on the research that has developed a user-friendly website to help guide women on how best to plan and prepare for pregnancy

There are plenty of women who still think that their choice regarding contraception is between pills and condoms, when, in fact, there are lots of other methods.

The disastrous 2012 Health and Social Care Act, which fragmented commissioning, and the slashing of local authority public health budgets have reduced the number of services provided – resulting in less access to some contraceptives

than there used to be.

We were delighted, therefore, to receive an NIHR commission in 2016 to improve uptake of long-acting reversible contraception (LARC) through helping women aged 15-30 to make a more informed choice.

The LARC options consist of arm implants, intrauterine devices (IUDs, or coils), and injections – all highly effective at preventing pregnancy. In fact, implants and IUDs are about as effective as sterilisation, whereas pills and condoms are much less effective by comparison.

For the commission, we took about 18 months to develop a website called Contraception Choices - <https://www.contraceptionchoices.org/>, after reviewing what was already out there and undertaking big systematic reviews of existing research, and understanding from the public about such things as what influences their choice of contraception. We then worked with young

women to get the website design, colours and layout right.

One of the key things about the website is that it's interactive. Having entered information about herself, a woman can then click on "What's right for me?" and have three methods suggested that should suit her particular circumstances.

For the feasibility trial, we recruited women from all the settings where contraceptive consultations take place – sexual health clinics such as the Margaret Pyke Centre run by CNWL general practice, the abortion service, maternity service and a community pharmacy.

Initially, a researcher asked young women

in these settings if they were interested in taking part in a study about contraception and recruited them online, using an iPad. It took about six months to hit our anticipated target of 400.

There were times when we'd be presenting the website to a clinic and women would say, "Wow, we want to use this now." But we didn't want to release the website at that stage because it was important to make sure the control group in our trial hadn't seen it.

However, the enthusiasm from the clinics made me think that promoting the link to the website to women prior to their consultation might be the way forward.

In the text confirming their participation, we added a link and said: "Before your visit, please take a look at this website to take part in online contraception research." The link would take her to the same page that would be seen by women being recruited face-to-face in clinic.

We recruited 530 women this way in six weeks, more than doubling the size of the trial. In total, we had 470 women who'd seen the website and 470 who hadn't. This meant that rather than doing a mini feasibility trial first, we could go straight to the big trial.

The first outcome we were interested in was whether seeing the website meant you were more likely to use a LARC method, and the second was to see how satisfied women were with whatever method they were using.

The comments were remarkably positive from all those who had seen the website, such as "I wish I'd seen this earlier", and "It's made me think about changing to a more effective method of contraception".

We had high hopes that we would see an effect on the clinical outcomes, but the short answer, disappointingly, is that we didn't. In the trial, the women were just as likely to be on a LARC method at six months, whether or not they'd seen the website.

Despite the findings, we knew that the women liked the website. And we were aware,



from reviewing a range of literature at the beginning of the study, that multiple factors come into play when deciding on contraception.

The information on the website is important, but it's also about what your partner and peers think, other stories you've heard about it, and practical things such as whether you're able to get an appointment with a GP or a clinic to have a LARC method fitted.

The next step is to think about how the website could best be used in practice.

The idea is that before attending a contraception consultation, a woman will

Continued on next page >>

Making research everybody's business



“Whether you have a pregnancy or not can profoundly affect you in many ways”

– Professor Judith Stephenson

>> Continued from previous page

receive a hyperlink in the text message confirming the appointment. They would then go on to the site and be able to see three methods that might suit them, then attend their appointment armed with this information to discuss with the nurse or doctor.

The other part of our research programme is to do with helping women prepare for a pregnancy that they do want – what we call preconception or pre-pregnancy health.

It's an area that health services haven't taken much interest in, partly because it's often assumed to be a private matter. Services are set up either for preventing pregnancies (family planning clinics) or for people being pregnant (maternity services). The big gap in between doesn't come under the scrutiny of the NHS.

The likelihood is that at least half of pregnancies in the UK are planned to some degree – and two-thirds of those that lead to a live birth are planned – yet we know very little

about how women prepare for pregnancy.

Whether you have a pregnancy or not can profoundly affect you in many ways – psychologically, emotionally, socially, culturally, economically and, possibly, professionally. So we have been studying how we can help and support women, and their partners, who don't plan and prepare for pregnancy.

In 2004, my UCL colleague Dr Geraldine Barrett developed a very useful pregnancy-planning tool called the London Measure of Unplanned Pregnancy – www.lmup.com.

Instead of saying in black and white terms whether a pregnancy is planned or unplanned, the LMUP grades it from 0-12, which means we can capture the range of ambivalent or more subtle feelings that many people actually feel about a pregnancy.

Antenatal services in the UK are, generally speaking, very high quality, and what has come into sharp relief in recent years is the challenge of the health problems women have as they enter pregnancy.



Photo: Joey Thompson on Unsplash

If a woman is a smoker, obese, has a mental health disorder or has high blood pressure, the risk of pregnancy complications and the health of the baby can increase. The “bookends of pregnancy” – the period just before you're pregnant and the period just after – need a lot more attention.

In April 2018, we published three papers in the *Lancet* – <http://bit.ly/2F3Ysj2> – to make the case for why we should be concentrating on these areas.

The first paper outlines why preconception health is important; the second is about how it affects not just the mother's health but also the health of the baby as it develops and after it's born; and the third lays out the kind of intervention strategies we need to improve preconception health.

Preconception wasn't on people's radar before, but it is now gaining traction and getting a higher profile.

A paper by Public Health England, called Making the Case for Preconception Care – <https://bit.ly/2lHpfgZ> – came out in July 2018, and drew heavily on the *Lancet* series we published.

That's the government coming out and saying we really need to do something about this, and I think that's going to grow.

New options put positive spin on 'smear' campaign

Concerns about the falling rate of uptake in cervical screening among women aged 50-64 has led to a research study that offers an easier and more acceptable way of testing for human papillomavirus (HPV).

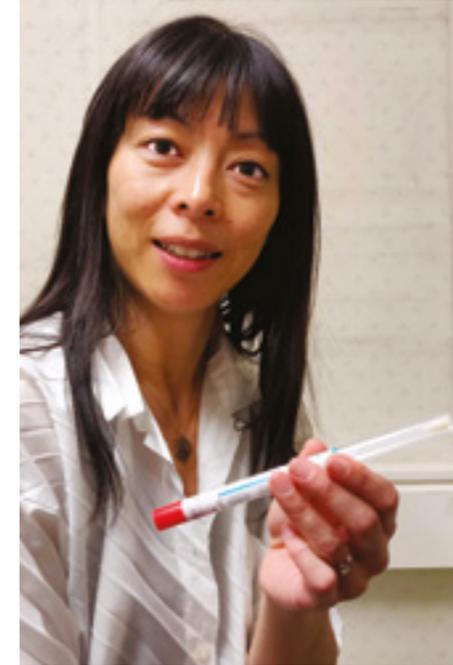
Cervical screening tests using a speculum -- the instrument used to hold open the walls of the vagina -- can be more uncomfortable for older and post-menopausal women.

Some women may also choose not to be screened because of embarrassment, busy lifestyles, and religious or cultural reasons.

Underscreened women are at highest risk of developing cervical cancer; hence the need to make screening for HPV – the virus that can cause cancer if left untreated – as acceptable and accessible as possible to all women.

The study in London -- led by chief investigator Dr Anita Lim, of the King's College London Cancer Prevention Group, and funded by Cancer Research UK -- will explore non-speculum alternatives, including both sampling by a clinician and self-sampling.

Self-sampling is already offered in other



Dr Anita Lim with a self-testing kit.
Photo: Andrew Perugia

countries, such as the Netherlands and Australia, enabling women to take a test themselves in private, at home, and without an appointment or examination.

Clinician sampling without a speculum has not been tried before, but will hopefully appeal to women who would still like the to have a test taken by a doctor or a nurse, but without the discomfort.

Both of the test options are expected to be at least as accurate as a standard cervical screening (smear) test.

The pilot study, which will involve 10-12 GP practices within the Barts Health NHS Trust catchment area, is open to women aged 50-64 who are eligible for cervical screening and who are at least 12 months overdue for a test but have been screened at least once in the last 15 years.

Tests will be analysed for HPV at Barts Health NHS Trust cytology laboratory, and residual samples will be sent to researchers at Queen Mary University of London for possible future biomarkers that may improve cervical screening in the future.

Making research everybody's business

Folly of falling out of the EU melting pot into the fire

Q&A: Martin McKee, professor of European public health at the London School of Hygiene and Tropical Medicine, adviser to the EC on health and a member of Scientists for EU, outlines fears about Brexit effects on NHS research

Q. What impact will Brexit have on health research in the UK?

A. There is a lot of uncertainty – we have no idea what’s going to happen because the prime minister also has no idea – but to do world-class research you need to have world-class researchers. It’s going to become much more difficult for leading universities to recruit internationally, and the proposed salary

threshold could deter young people.

Some researchers are looking to move away from the UK, to Ireland or the Netherlands in particular; and some have already moved. People are much less willing to apply for posts.

The most immediate problem is going to be our ability to recruit and retain researchers as the UK is increasingly becoming an unwelcoming place to work. This is unsurprising because, until recently, it has been explicit government policy to create a hostile environment to migrants.

Brexit would also lead to a vast increase in bureaucracy for those who want to come to work here, such as applying for settled status, applying for work permits. That will create a barrier that people don’t face elsewhere within the EU.

Then there’s the issue of the lack of long-term security for researchers and their families.

Working here while your family stay in France or Germany, say, is not an attractive proposition.

Thinking more long-term, will the qualifications and experience researchers gain in the UK be recognised when they go back to the countries from which they’ve come?

Many people, such as young women who become pregnant, use the cross-border healthcare directive to go home to have their babies, but would they still be able to do that? And if they have an elderly relative who needs care, would they be able to bring them to the UK? The potential consequences for family life are profound.

Q. How will funding for research be affected?

A. A no-deal Brexit would mean we will be entirely cut off from all EU funding. If there is a deal, the best we can hope for is that we will continue to participate in the EU research and innovation programme Horizon 2020, but we would be probably be excluded from the Erasmus EU student exchange programme, and would definitely be excluded from European Research Council funding.

The ability to participate in the networks will also be a problem. I’m currently involved in a Horizon 2020 bid that has got through to the second round, but, because of the uncertainty, I am likely to participate through one of my affiliations in continental Europe, rather than the UK. And, of course, the UK will not be able to lead these types of projects.

Funding from within the UK will also be hit. We’ve already seen that the economy has grown substantially slower than it would have done had we not had the referendum, and every credible forecast predicts that the economy will shrink even more.

Q What difference will Brexit make to patients?

A. The immediate consequence is going to be access to medicines. In the last few months, we’ve realised just how precarious the complicated pharmaceutical supply chain system is, even at the best of times. Medicine shortages are much more problematic than food shortages – if you don’t have chicken you can eat fish instead, but you can’t substitute medicine.

The government opened a depot in Belgium to store drugs and other medical supplies, and has agreed to pay £88.8m to ferry companies



to transport them to the UK in the event of a no-deal Brexit.

Then there is the £33m out-of-court settlement paid to Eurotunnel because of a failure to operate the tender process lawfully.

That money could be better spent on other things. We’ve submitted a freedom of information request to try to find out about the planning assumptions on medicines supply, but we’ve been unsuccessful. The Commons Health and Social Care committee has also failed in its attempts to get any concrete information.

As Caroline Lucas MP has pointed out, the government has given the contract for control of the shipping routes to DHL, the company responsible for failing to deliver chicken to KFC restaurants last year, so that doesn’t inspire a great deal of confidence.

Q. How will it impact your work?

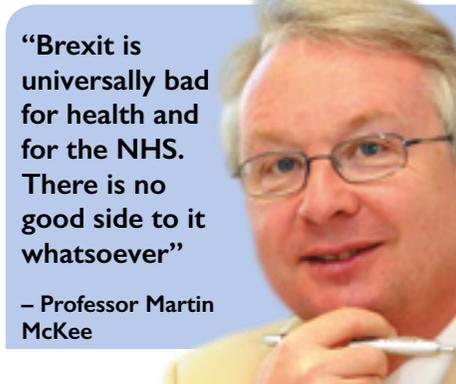
A. It will be much more difficult for us to continue European collaborations, and delays at borders will make travelling to meetings on the continent much more complicated.

Q. Has Brexit affected the goodwill between UK and European researchers?

A. Our European colleagues realise that the UK health and scientific communities were overwhelmingly opposed to Brexit, so we’ve had nothing but support from them. I think the overriding impression is one of pity.

A number of my colleagues – particularly those who trained in the UK and look at it as a country that is well governed and has institutions that work, and which they seek to emulate – have almost had a bereavement reaction. Many people have pointed out the enormous damage that has been done to our international reputation. They find it incomprehensible.

Brexit is universally bad for health and for the NHS. There is no good side to it whatsoever. The UK will undoubtedly re-join at some stage – young people are overwhelmingly in favour of being within the EU – so that makes you wonder why we’re wasting our time.



“Brexit is universally bad for health and for the NHS. There is no good side to it whatsoever”

– Professor Martin McKee

Service users earn pride of place in PP research

A bold initiative developed at the East London NHS Foundation Trust has enabled mental health service users to carry out research into the benefits of People Participation (PP) teams – while improving their own health and well-being at the same time.

The PRIDE (Participation, Engagement, Involvement, Recovery and Experience) project, funded by a grant from the Centre for Public Engagement at Queen Mary University of London, adopted a novel approach that goes way beyond the usual involvement of service users in research.

Normally, they would be involved in an advisory capacity or as additional members of an established research group.

Instead, PRIDE recruited a group of 15 service users – each with a least one year's experience of being involved in a PP team – to develop the project's design, materials and methods through workshops.

Three were then trained to manage day-to-day activities, carry out research interviews, analyse the data and author a peer-reviewed

paper, with the support of experienced professional researchers.

The project findings showed that PP initiatives can really benefit some patients and help their recovery through a positive effect on self-confidence, feeling valued, obtaining or refreshing personal skills, overcoming personal fears, and developing better ways to cope with their mental health problems.

"I set myself boundaries because I guess we all live in our own safety nets when you have mental illness," said one participant. "[PP] actually makes me go to the edge, and sometimes over. And when I do that, I feel like, 'Wow, I'm so glad I did that! I can really do that, you know.'"

Positive feedback from participants often focused on a desire to "give something back". As one said: "I felt a sort of passion in wanting

to help improve things. I felt sort of a need to pay back some of the really great professionals I met across the years who'd helped me out."

Another said: "It's helped me because it's made me think about what are the good things in life, what are the bad things, and what's going to keep me well and safe and keep me from going back to hospital again."

Participants also suggested that "moving on" support systems – including careers advice – should be part of PP programmes to help people who have engaged in and benefited from such involvement to progress to

the next step by pursuing their goals in terms of employment and social inclusion.

The benefits indicated by PRIDE lend weight to the case for larger-scale studies on further developing the model of PP teams that are being established across the UK.



Pathways to training opportunities

The following sessions are being hosted by Noclor and our associates. All the sessions are free and open to all staff who have an interest in research (including doctors, dentists, nurses, research assistants) and who are working in, or are associated with, our partner trusts.

- **Critical Appraisal Skills Training Workshop**
(Qualitative Sessions)
Monday, 25 March
10.00-13.00
Monday, 10 June
10.00-13.00
Monday, 24 June
10.00-13.00
 - **Essential Skills for Conducting Effective Clinical Research**
Tuesday, 26 March
9.30-17.00
Tuesday, 25 June
9.00-17.00
Wednesday, 27 March
13.00-17.00
Wednesday, 27 June
13.00-17.00
 - **Setting up and Managing the Trial Master File**
Friday, 29 March
9.30-13.30
Thursday, 28 June
9.00-14.00
Principal Investigator Training
Wednesday, 27 June
17.00-20.00
- All these courses will be held at **St Pancras Conference Centre, St Pancras Hospital, 4 St Pancras Way, London NW1 0PE**

To register or find out further information about our free training sessions, please visit our Eventbrite page via: www.noclor.nhs.uk/training-resources
All our training sessions are advertised on our Eventbrite page.

RESEARCH RAISES NEW HOPE OF TREATING MEMORY LOSS

The development of new therapeutic molecules by Canadian researchers at Toronto's Centre for Addiction and Mental Health shows great promise in reversing the memory loss linked to depression and ageing.

The molecules not only rapidly improve symptoms, but also appear to renew the underlying brain impairments causing memory loss.

Although the medication has so far been tested only on mice, the positive results mean that plans are being developed to trial it with people with depression, and then with older patients.

Dr Etienne Sibille, the lead researcher, says developing medications to deal with these issues has been notoriously difficult. However, he believes the new drug could be administered as a pill to anyone in their late 50s at risk of cognitive problems in old age.

noclor

RESEARCH SUPPORT

Projects currently recruiting

● THRIVE

A virtual reality (VR) treatment trial aiming to help build the confidence of people who have a persecutory delusion and feel threatened when with other people.

Using VR to replicate real scenarios, the goal is for patients to be able to cope with entering feared situations, and transfer the learning to everyday life.

contact.noclor@nhs.net

● GLAD

Recruitment of at least 40,000 patients via GP practices to help towards creating the largest recontactable biobank of participants diagnosed with depression and anxiety, the two most common psychiatric disorders worldwide. The aim is to help develop better treatments by exploring genetic and environmental factors associated with risk of the disorders.

noclor.norththamescrn@nhs.net

First Floor, Bloomsbury Building,
St Pancras Hospital, 4 St Pancras Way,
London, NW1 0PE

TELEPHONE **020 7685 5949**

EMAIL **contact.noclor@nhs.net**

URL **noclor.nhs.uk**

 **twitter.com/NoclorResearch**

Editorial content:

David Clare & Katie Shimmon

This paper is Forest Stewardship Council certified

Key Contacts

The Noclor Research Support team is here to help you with research. So please feel free to contact our various teams.

For queries relating to Research Management and Support:

contact.noclor@nhs.net

Funding and Finance queries:

finance.noclor@nhs.net

Looking for advice with or interested in a project in Primary Care? Contact:

primarycare.noclor@nhs.net

Keen to learn more about our free training courses, or to offer content suggestions for future Noclor publicity material? Contact:

irina.grinkova@nhs.net

If you would like to get in touch with our Service Director, Lynis Lewis, please contact:

irina.grinkova@nhs.net